Submission to the Australian Law Reform Commission

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[redacted]

27 June 2025

The Commissioner
Australian Law Reform Commission
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Dear Commissioner,

SUBMISSION TO THE AUSTRALIAN LAW REFORM COMMISSION – REVIEW OF THE HUMAN TISSUE ACT (Issues Paper 2025)

ALRC Review of Human Tissue Acts (HTAs)
Focus Area: Reproductive Tissue and Donor Conception

Submission: Human Tissue Law Reform – Reproductive Tissue and Gametes

Background

My name is Melissa Sharman, and I welcome the opportunity to contribute to the consultation on human tissue law reform, particularly in relation to reproductive tissue such as gametes.

I am the founder of Egg Donation Australia—a national support network that represents over 16,000 individuals including egg donors, recipient parents, donor-conceived people, and professionals navigating the donor conception landscape. I also have deeply personal experience in this space, having been an egg donor and a three-time surrogate, helping create 22 children over the past 15 years.

Since the inception of the *Human Tissue Act 1982*, Australian society has undergone significant changes. Parenthood now occurs later in life, family structures have diversified with an increase in same-sex couples and solo parents, and infertility rates have risen. These realities intersect with a growing demand for donor conception.

With at least 2,500 births via donor gametes each year, and over an estimated 100,000 donor-conceived individuals living in Australia, it is clear that reproductive tissue is no longer a marginal issue—it is central to contemporary reproductive medicine and family formation.

Yet our legislative framework has not kept pace. Despite a national inquiry in 2011, most recommendations remain unimplemented. We still lack national legislation, a national donor register, or clear standards around informed consent, reimbursement, or recordkeeping. Instead, we have eight states and territories with inconsistent or absent regulation, and a self-regulated ART sector where interpretation of the AHMAC Guidelines varies widely.

Reproductive Tissue and the Law

Q1: Do you believe reproductive tissues (like eggs, sperm, embryos) should be included in the scope of this law reform? Why or why not?

Gametes should be treated with distinct and deliberate care due to their unique capacity to create life and the lifelong ethical, social, and legal consequences that follow. Unlike tissue used for transplantation or research, gametes can result in the creation of new individuals—individuals who grow up with a right to identity, family history, and access to accurate information.

It is inappropriate for gametes to be governed under generic tissue legislation. Instead, they require **dedicated, standalone legislation** that intersects meaningfully with reproductive technology, family law, and child rights frameworks. While a tiered or contextual approach to defining "human tissue" may still be useful—for example, distinguishing between tissue for transplantation, reproduction, research, and nutrition (like breast milk)—gametes must be acknowledged as a distinct category requiring dedicated ethical and legal oversight.

Q2: Have you experienced or observed any problems caused by inconsistent laws between Australian states and territories when it comes to gamete donation or donor conception?

Yes — in both my personal and professional capacity navigating donor conception across three Australian states, I have witnessed a deeply fragmented and inconsistent legal and regulatory landscape. This creates confusion, inequity, and risk for donors, recipients, and ultimately for donor-conceived people themselves.

Key inconsistencies include:

- **Advertising restrictions:** Donor recruitment advertising is allowed in some states (e.g., NSW) but heavily restricted or ambiguously regulated in others (e.g., Victoria). This deters potential donors, leaves recipients unsure of what is lawful, and complicates the work of advocacy groups trying to promote ethical, altruistic donation.
- **Reimbursement standards:** There is no nationally agreed definition of "reasonable expenses." This ambiguity leads to under-compensation for donors and creates ethical grey zones that undermine the spirit of altruistic donation.
- **Clinic practices and interpretation of guidelines:** ART clinics apply the NHMRC Guidelines inconsistently. I have observed significant variation in how clinics interpret donor family limits, the depth and quality of counselling, and informed consent processes.
- **Donor conception registers:** Until recently, most states lacked donor conception registers. There has been some progress in Queensland, NSW, ACT, and SA to catch up, but gaps remain in education, support, and long-term care provided by these systems. In many cases, there has been limited public consultation, and in some states, responsibility for these registers has been given to organisations historically overseeing adoption — which, while sharing some parallels, is fundamentally different from donor conception and requires specialised knowledge.
- **Legal and administrative oversight:** Only a few states have robust legal frameworks, and even these are inconsistently funded and supported. The recent defunding of VARTA — once a leader in donor education and support — shows

how fragile these systems are. There is no centralised national oversight ensuring lifelong education, transparency, or coordinated post-donation support.

- **Consent rules:** There are notable differences in when donors can withdraw consent. For example, in Queensland, donors cannot withdraw consent after fertilisation; in Victoria, donors may withdraw consent up until the embryo is transferred to a uterus. This creates confusion and potential distress for donors and recipients alike.
- **Additional inconsistencies:**
  • Some states (e.g., Victoria) require intended parents to complete police checks, while others do not.
  • The Northern Territory still has no legislation at all governing donor conception.
  • Wait periods after donation vary by state.
  • Counselling requirements also vary dramatically: some states require multiple, sometimes excessive sessions; others offer only checkbox-style assessments that don't properly explore the complex implications of donor conception.
  • Some counsellors facilitating these processes lack in-depth understanding of donor conception, and members of the donor community, including myself, have often needed to step into an educator's role to ensure proper information and support are provided.

Together, these inconsistencies create real and ongoing harm: they deter donors, increase emotional and financial strain on families, and undermine the ethical foundation and integrity of Australia's donor conception system. A national, consistent, and evidence-based framework is urgently needed to protect everyone involved — and most importantly, to prioritise the lifelong rights and wellbeing of donor-conceived people.

Donor Conception Registers

Q6: Do you think there should be a national donor conception register? If so, what should it include?

Donor-conceived people have a fundamental and lifelong right to know the truth about their genetic origins. This right is essential for identity formation, medical history, psychological wellbeing, and the development of secure and authentic family relationships. It must be recognised not as optional or conditional, but as intrinsic to the dignity, autonomy, and humanity of each donor-conceived person.

Specifically, donor-conceived people should have the right to:

- Access identifying information about their donor once they reach a reasonable age (e.g., 18), with appropriate safeguards for privacy and emotional wellbeing.
- Access non-identifying information from birth, including the donor's medical history, physical characteristics, cultural background, and reasons for donation.
- Receive timely updates if the donor develops or learns of new hereditary conditions or relevant medical information after donation.
- Connect with donor siblings (with mutual consent) to help form a clearer sense of identity and to reduce the risk of accidental consanguinity.
- Receive professional emotional and counselling support when accessing this information, especially for those whose conception was not disclosed early.
- These rights must be enshrined in law, nationally harmonised across all states and territories, and supported by a central, well-resourced donor conception register.

Currently, in all states except Victoria (where there is at least an asterisk noting more information may be available on their birth certificate), it remains entirely up to parents to disclose to their child that they are donor conceived. If parents choose not to share this information, it is unlikely the child will ever know. This reality has significant consequences:

Many donors hesitate to donate under identity-release models because they feel there is a strong chance the child will never be told, making identity release meaningless.

Donor conception community estimates suggest around two-thirds of donor-conceived individuals still do not know of their origins — a pattern that began decades ago but sadly still persists today, despite education around best practice disclosure.

In conversations with donor-conceived adults and young people, I have repeatedly heard about the deep psychological harm of discovering the truth by accident — often through ancestry DNA tests or late family disclosure. This late discovery can lead to shock, grief, and long-term psychological distress.

There is also a modern risk that has become increasingly real for donors, donor-conceived people, and their families: in an age of dating apps and social media, the chance of unknowingly connecting with a biological sibling, cousin, or even half-sibling has become a genuine concern. For example, in my own situation, my biological children are only a few years older than my donor-conceived offspring. Had I not chosen to be a known donor, the possibility of them unknowingly meeting — and potentially dating — would have been very real. This highlights why transparent systems, early disclosure, and connection between donor siblings are more critical than ever.

Registers alone are not enough if donor-conceived people do not know to look. Ultimately, donor-conceived individuals are not simply outcomes of a reproductive procedure; they are people with lifelong identities, rights, and needs that must be fully respected and protected by law. A truly ethical donor conception system must ensure openness, honesty, and lifelong access to the truth of one's origins — for the health, safety, and dignity of all involved.

Without a national register, we fail to protect the identity rights of donor-conceived people and risk ongoing harm due to lost, inconsistent, or inaccessible records.

Advertising, Trade and Ethics

Q7: How should Australia regulate the advertising or recruitment of gamete donors?

Australia should regulate donor recruitment through a **national, transparent, and ethical framework** that supports informed, voluntary participation while protecting all parties involved.

Key recommendations include:

- **Legal clarity**: All states and territories should permit responsible advertising for gamete donors. Current discrepancies—where advertising is legal in some jurisdictions but restricted or ambiguous in others—create confusion, deter donors, and disadvantage recipients.
- **Ethical guidelines**: Advertising should be **truthful, respectful, and non-coercive**. It should avoid misleading claims, emotional manipulation, or promises of financial gain.
- **Standardised information**: Ads should include clear information about:
    - The altruistic nature of donation
    - The time, medical procedures, and commitment involved
    - Potential lifelong implications (e.g., future contact, identity release)

    - Reimbursement of reasonable expenses (not payment for donation)

- **Access for diverse family types**: Recruitment should not discriminate based on relationship status, sexual orientation, or gender identity. Inclusive language and outreach are essential to reflect Australia's diverse families.
- **Community-led models**: Individuals and advocacy groups should be allowed to connect through moderated online forums or social platforms, provided advertising meets national standards. Criminalising peer connection harms community education and empowerment.
- **Clinic responsibility**: ART providers should be required to use approved recruitment materials and participate in public education campaigns. Clinics should not use competitive or profit-driven incentives that distort the altruistic intent of donation.
- **Oversight and transparency**: A national body should oversee donor recruitment, including reviewing materials, monitoring complaints, and ensuring compliance with ethical and legal guidelines.

By regulating recruitment with consistency, transparency, and respect for autonomy, Australia can build a donor system that is ethical, sustainable, and responsive to modern family formation.

Q8: What are your views on paying people for donating reproductive tissue?

I strongly support an **altruistic model or a compensated model** (such as used in the UK and Canada) of gamete donation—**not a commercial one**—but this must be underpinned by a fair, nationally consistent reimbursement framework.

Key views:

- **No commercialisation**: Paying people for their gametes risks commodifying human life and exploiting vulnerable individuals, particularly women from lower socio-economic backgrounds. This undermines the deeply personal, relational, and lifelong implications of reproductive donation.
- **Support for altruism through reimbursement**: Altruism must not mean donors are left out of pocket. Many donors incur **significant direct and indirect costs**—

including time off work, childcare, travel, accommodation, and emotional labour. These should be reimbursed fully and fairly.

- **National consistency**: The current lack of clarity on what constitutes "reasonable expenses" results in under-compensation, legal uncertainty, and regional inequity. A **national schedule of reimbursable items**, backed by law, would protect donors and recipients alike.
- **Avoid hidden incentives**: Some clinics offer "loss of income" payments or generous 'reimbursements' that blur the line with financial inducement. Clear, transparent, and capped reimbursements must replace vague, clinic-driven interpretations.
- **Protect donor intent**: True altruism thrives when the process is transparent, safe, and respected. Enabling donors to give without financial harm strengthens trust in the system and honours the ethical foundation of donor conception.

Australia must preserve its commitment to altruism, but do so in a way that **values the contribution of donors, removes financial barriers, and maintains ethical integrity**.

Q10: What values do you think Australia's laws on reproductive tissue donation should be based on?

Australia's laws on reproductive tissue donation should be grounded in a core set of values that protect the rights and dignity of all parties involved — especially donor-conceived people — while promoting ethical, equitable, and transparent practices. The following values should underpin reform:

1. **Respect for Autonomy**
   Individuals should have the right to make informed, voluntary decisions about the donation, use, and storage of their reproductive tissue. Consent must be ongoing, specific, and revocable, especially as technology evolves or new uses arise.
2. **Transparency and Accountability**
   The system must operate transparently, with clear record-keeping, disclosure obligations, and regulatory oversight. This includes ensuring donor-conceived people can access accurate, complete information about their genetic origins.
3. **Equity and Fair Access**
   Laws should promote equitable access to assisted reproductive technologies and avoid creating a two-tiered system based on socioeconomic status, race, geography,

or sexual orientation. This includes fair treatment of donors, recipients, and donor-conceived individuals.

4. **Welfare of the Child**
   The best interests of the donor-conceived person must be a central guiding principle — not only in childhood but across the lifespan. This includes rights to identity, kinship knowledge, and protection from commercial exploitation.
5. **Non-Commercialisation of the Human Body**
   Human reproductive tissue should not be treated as a commodity. Legal frameworks should prevent profiteering while still recognising and valuing the time, effort, and bodily contribution of donors, potentially through regulated reimbursement or recognition mechanisms.
6. **Privacy and Data Protection**
   Sensitive genetic, personal, and health data must be securely managed, with clear limits on its use. Emerging technologies such as AI or genetic matching must be carefully regulated to ensure privacy is not compromised.
7. **Inclusivity and Cultural Sensitivity**
   Laws must account for diverse family structures and cultural perspectives, including those of First Nations peoples. Respecting cultural beliefs around kinship, ancestry, and bodily integrity is essential to a just system.
8. **Future-Proofing and Flexibility**
   The legal framework must be adaptable to scientific developments, emerging ethical concerns, and changing social norms. Principles-based legislation, supported by responsive regulation, is essential to avoid reactive or fragmented reform.

Embedding these values into Australia's legal approach will help build a system that is not only functional but just — one that acknowledges the human realities behind reproductive technologies and protects all participants equally.

Final Thoughts

Q11: Is there anything else you want the ALRC to know about your experiences or suggestions for reform?

Yes. Having spent nearly two decades involved in donor conception as a donor, parent, advocate, and supporter of intended parents and donor-conceived people, I believe the

ALRC should understand just how profoundly the current fragmented and inconsistent system affects real families and real lives.

Key suggestions for reform include:

A single national framework: We urgently need nationally consistent legislation governing donor conception — covering advertising, donor registers, family limits, counselling standards, withdrawal of consent rules, and rights of donor-conceived people to information. The current patchwork of state laws creates confusion, inequity, and risk.

Mandatory early disclosure support: The law should do more than encourage parents to tell; it should include structured, supported disclosure processes so donor-conceived people learn the truth about their origins in childhood — before adolescence or adulthood, when discovering by accident can be deeply damaging.

A national, well resourced donor conception register: This register should actively link donors, donor-conceived people, and siblings (with consent), hold updated medical information, and provide access to qualified counselling and support over the lifespan. Registers are only meaningful if people know to use them — which depends on disclosure and education.

Better education for professionals: Counsellors, clinic staff, and lawyers involved in donor conception should receive mandatory, specialist training. Too often, community members like myself end up educating professionals who should be guiding families.

Public consultation and co-design: Reform should meaningfully involve donor-conceived people, donors, and recipient parents. Decisions about laws and systems must be informed by the people who live with their consequences.

Finally, I urge the ALRC to remember that donor conception is not simply a medical service; it is the beginning of lifelong family relationships and identities. Policy must centre not just the process of conception but the lifelong wellbeing, identity, and safety of donor-conceived people — and the real families formed through donation.

Thank you for the opportunity to contribute.

Melissa Sharman

Founder – Egg Donation Australia